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Living with prostate cancer

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Chapter 7

Determinants of participation in social support groups for prostate cancer patients

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Nee. Ik heb het zelf verwerkt allemaal en als je in zo'n gespreksgroep gaat zitten, word je ook met je eigen ziekte weer geconfronteerd. En nu heb ik het zelf een plekje gegeven, waar ik dus goed mee om kan gaan en die twee vrienden die ik dan heb bijvoorbeeld, die geven mij ook, en wederzijds, psychologische steun.

(Respondent 149)

Psycho-Oncology 2007, 16, 1092-1099

Abstract

Objective

This study aims at determining factors related to the intention to participate and actual participation in social support groups for prostate cancer patients, using the framework of the theory of planned behavior. The factors studied are background variables, medical variables, psychosocial variables and attitude, social norms and perceived control.

Methods

From various sources, 238 prostate cancer patients were recruited. The patients filled out a questionnaire, containing standardized instruments on several psychosocial problems and social support, besides questions on demographic and medical characteristics. A specific questionnaire was developed to assess attitude, social norms and perceived control concerning participation in support groups. From the recruited men, 48 participated in one of the support groups organized by the researchers.

Results

Logistic regression revealed that age, lack of social support, a positive attitude and a high perceived control are predictive for the intention to participate in a social support group. Perceived control and the number of prostate-specific problems did predict the factual participation.

Conclusion

Many prostate cancer patients report psychosocial problems. A more positive attitude toward group participation and the availability of support groups at short travel distance facilitates the interest in and the factual group participation.

Practical implications

Urologist and urological nurses can play a role in creating a more positive attitude towards group participation, especially if the social support system is weak. Groups should be organized close to patients' place of residence.

Introduction

Prostate cancer is a disease with a high incidence in western countries (Black et al. 1997; Landis et al. 1998; Visser et al. 2002). Over the past decades, research has shown that, besides physical complaints, psychosocial problems are frequently present in men with prostate cancer. Although anxiety is a problem in only 3% of the patients during the diagnostic process (Essink-Bot et al. 1998), after treatment for localized prostate cancer, fear, worries, sleep disturbance are found in 50% of the patients (Schag et al. 1994). Post traumatic stress disorder is present in 14% of the patients (Bisson et al. 2002) and feelings of isolation are found in 20% of the patients (Helgason et al. 2001). Studies on depression show a prevalence of depression in 13% of men with metastasized prostate cancer (Pirl et al. 2002). Family and social life are negatively impacted by incontinence or an increased urination frequency (Kornblith et al. 1994).

Social support is an important factor in dealing with these psychosocial problems of the patients and is helpful to adapt to prostate cancer and its treatment. Studies among prostate cancer patients indicate that social support leads to better mental health (Lepore & Helgeson 1998; Eton et al. 2001), less psychological distress (Baider et al. 2003) or even prolonged survival (Krongrad et al. 1996). A major source of social support is the direct personal social environment, especially the spouse (Kornblith et al. 1994). For a growing group of prostate cancer patients, support groups, either a self-help or a professionally led groups, are becoming a way to find social support.

A common feature of these groups is the emphasis on education and information exchange (Feldman 1993; Gray et al. 1996; Coreil & Behal 1999) although sharing of personal emotions is also valued. The groups are mostly very positively evaluated by participants (Gray et al. 1997; Feldman 1993; Coreil & Behal 1999) and studies found a positive effect on psychosocial well-being (Lepore et al. 2003; Grégoire et al. 1997) or even improvements in immune parameters (Carlson et al. 2003).

Despite the growing availability of prostate cancer support groups (Weber et al. 2000; Grégoire et al. 1997; Poole et al. 2001; Gray et al. 1996), there is a discrepancy between the need for support and the actual use. A study on care and support needs in prostate cancer patients shows that between 10% and 17% of the patients wanted a form of psychosocial support while 3% to 9% actually used these kinds of support (Lintz et al. 2003). A pilot study in the Netherlands point out that where 29% of the patients feel the need for support, only 9% actually participated (Voogt et al. 2001).

The need for support is obviously higher than the actual use of support. Knowledge about this discrepancy between need and use as well as the decision process in men with prostate cancer to actually participate in social support groups, is scarce. Voogt et al. found that lower age, lower quality of life, more mood disturbance and higher levels of traumatic stress symptoms are related to a higher need for support (Voogt et al. 2001). Taylor (1986) found cancer patients with higher education to be more likely to attend support groups (Taylor et al. 1986). Also higher education and physician referral were found as predictors of participation in support groups in an American population (Eakin & Strycker 2001).

The question that rises is why so few men show interest in support groups, despite the fact that many men experience psychosocial problems. More knowledge about the factors that influence the need for and the actual use of social support groups may lead to insight in the psychological and the practical barriers for participation of prostate cancer patients in support groups. Based on this information, interventions can be developed or advice can be formulated to make these support groups available for more prostate cancer patients.

The aim of this study is to examine factors that determine the interest in and the actual participation in a social support group for men with prostate cancer. The applied theoretical framework for studying determinants of support group participation is based at the theory of planned behavior (Ajzen 1991). According to this theory, the intention to exhibit a certain behavior is a function of the attitude and the social norms towards that behavior. In addition, the perceived control is related to the behavioral intention and directly to the behavior itself. Applied to the current study, the intention to join a support group may be a function of the attitude towards support groups, the social norms about attending support groups and the perceived control, whereas the actual participation is a function of the intention and the perceived control. The applied model for the study on the determinants of the support group participation is depicted in Figure 1.

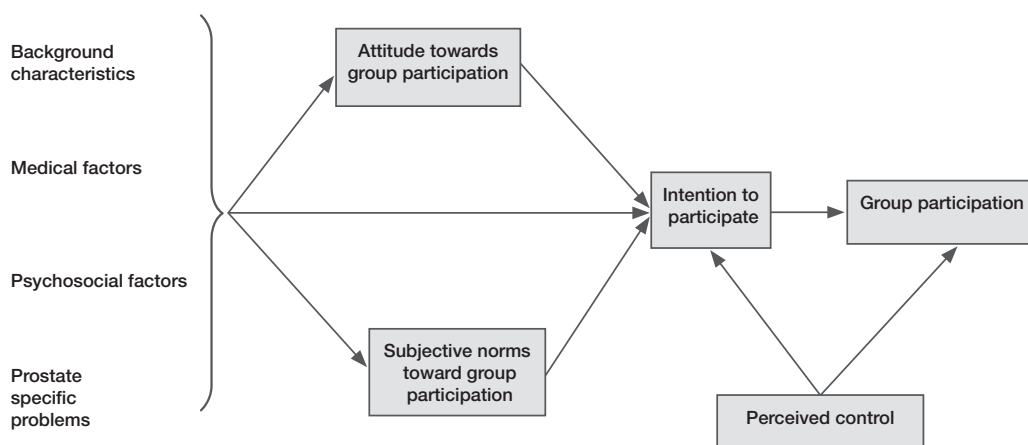


Figure 1. The applied model for studying the participation in social support groups

From this model, it can be derived that - apart from background variables, medical factors, psychological distress and social support and prostate specific problems - attitude, subjective norms and perceived control can play an important role in the development of interest and participation in social support groups. According to the Fishbein and Ajzen model, attitude and social norms are related to the behavioral intention and not to the behavior itself.

Methods

Recruitment of participants

This study is part of a larger research project on health-related quality of life, psychosocial problems and need for psychosocial support in men with prostate cancer. The medical ethical committee of the Onze Lieve Vrouwe Gasthuis Amsterdam approved the study. For the recruitment of patients, folders with a response card were used, providing information about the study and the request to participate by completing a series of questionnaires. The folders were handed out by urologists in five hospitals and distributed at three educational meetings about prostate cancer. There was also a direct mailing to all members of the Dutch prostate cancer patients association. An announcement of the research project and the support groups was made on a Dutch internet site on cancer (www.kanker-actueel.nl) and an advertisement was placed in a local newspaper. A folder was sent to men who reacted on the internet site or the advertisement. When an affirmative response card was received, either a questionnaire was sent by mail or, when the person indicated wanting to participate in a support group, the person was called to schedule an intake preceding group participation. Inclusion criteria for the study were having prostate cancer in any stage, speaking and reading the Dutch language sufficiently to understand the questionnaires. Exclusion criteria were having another type of cancer or a serious disease that impairs the health related quality of life. These criteria were obtained from medical files and patients self reports.

Measurement instruments

To determine the background characteristics, questions were asked about date of birth and marital status. The measure of socio-economic status is based the level of education (three categories), annual income (four categories), and job level (five categories). The alpha coefficient is .84. Membership of the patients association was determined by checking the members list. The medical files of the patients were used to get information about the stage of the disease.

As a measure of general psychosocial distress, the shortened Dutch version of the profile of mood states (POMS) was used (Wald and Mellenbergh 1990). The POMS has five subscales with good Cronbach's alphas in our study. The scales concern depression ($\alpha = .92$), anger ($\alpha = .91$), fatigue ($\alpha = .90$), tension ($\alpha = .88$), vigor ($\alpha = .78$). The total score was also used as a general psychological distress score ($\alpha = .95$).

Symptoms of posttraumatic stress disorder (PTSD) are assessed by the impact of events scale (IES) (Horowitz et al. 1979). The instructions were to consider the prostate cancer as the traumatic event. The IES contains a subscale on intrusive thought ($\alpha = .87$) and on avoiding behavior ($\alpha = .83$). The total score is used as measure of traumatic distress, ($\alpha = .90$).

Social support is measured by two questionnaires. First, the social support list (SSL) was used to measure lack of general social support. This questionnaire has different scales for lack of support, support in daily living, lack of emotional support, lack of approval, lack of instrumental support, lack of companionship and lack of informational support. The total score is used as a general measure of lack of social support ($\alpha = .96$) (Van Sonderen 1993). A second questionnaire on disease-specific social support (De Haes 1988) was used, which has two subscales. One scale concerns support provided by family, friends and medical staff that is directly related to the disease ($\alpha = .74$). The other scale measures contentment with the information, treatment and support from the hospital ($\alpha = 0.86$).

A questionnaire about specific problems for prostate cancer is based on the Needs and Use of Psychological care facilities Questionnaire (PNUP-Q) list, a measure of supportive care needs (Osse et al. 1999). Our adjusted version of the questionnaire consists of nine items covering the following areas: physical problems, problems in communicating with others due to the disease, financial difficulties, feelings and emotions, communication with medical staff, problems with sexuality, micturation problems, problems with activities of daily life, problems with concentration and memory. It is asked whether patients have problems in this area and whether they want to talk about this and with whom. The measurement of attitude, social norms and perceived control is derived from the theory of planned behavior (Ajzen 1991). There is no existing standard questionnaire, however, the theory provides guidelines how to construct a such questionnaire.

The measurement of attitude is based on a combination of six beliefs about group participation and the six items on the evaluation of that belief. These items were chosen based on brief interviews with patients about their ideas on support groups. Six beliefs are formulated in the form of expectations or statements: 1. Do you expect that group participation lead to new ways to deal with you disease; 2 do you expect to get new information about your disease from a support group; 3. Do you think you can expand your social contacts by joining a support group; 4. Do you expect emotional issues to be a topic during the sessions; 5. Do you think you will have to deal with problems of others during the group sessions; 6. Do you think other people might disapprove of you if you participate in a support group. The belief items are rated from -2 (not at all) to + 2 (very much). Corresponding six items are about the evaluation of these beliefs, for example 'new ways of dealing with my disease are': rated -2 absolutely unimportant to +2 very important. The product of the belief and the evaluation of that belief is considered the attitude towards group participation. The attitude scale is formed by the mean of the five different attitudes, ranging from -12 to + 12. This scale has a Chronbach's α of .76. For the subjective norms scale, a similar procedure was followed, using four statements how important others (spouse, children, best friend, urologist) might view participation and five ratings of the tendency to comply. This scale has a range from -8 to + 8 and has a reliability of .68. Perceived control is measured by three items on the perceived practical possibilities for participation (travel distance, health and time investment), ranging from -2 to + 2 with a reliability of .60.

The indicator of the interest to participate in a social support group is based at three measures. First, all men who wanted to enroll in the study as participants in the social support group are considered as 'having interest' in participating in a support group. Second, in the questionnaire one item was asking whether men had been searching for different kinds of support. Men who indicated to have looked for a support group are also categorized as having the interest to participate in the support group. Third, the PNUP-Q list indicates the interest in getting social support for nine earlier described prostate cancer specific problems. All men indicating the intention to discuss one or more problems very much in a professionally led support group, are categorized as intending to participate in a support group. The Cronbach's α of this total score is .82.

Finally, men factual participating in a support, are the men who participated in most of the seven sessions of the support groups organized by the researchers.

Analysis

In order to be able to predict the intention and the actual participation in the social support group, the sample is divided in two groups based on the presence or absence of the intention to participate in a support group. The group that has the intention to participate is also divided in a group of men who actually participated and men who did not participate in one of our support groups. Two logistic regression analyses were carried out. The first analysis use the intention to participate as dependent variable and as independent variables the background characteristics, membership of the patients association, the medical characteristics, the psychological distress, the social support, the prostate specific problems, the attitude, the perceived social norms, and the perceived control. The second analysis has actual participation as dependent variable and background characteristics, membership of the patients association, medical characteristics, psychological distress, social support, prostate specific problems and perceived control as independent variables. We used the components of the model depicted in Figure one as predictors for interest and factual participation in support groups. In all analysis the back step conditional method was used.

Results

In total, 784 folders were distributed, 224 in hospitals, 142 at educational meetings and 418 to the members of the patients association. A total of 303 (39%) affirmative response cards were returned to the researchers. From these, 18 men dropped out after we tried to schedule an intake for the support groups because they changed their mind or were unable to participate in the study. So 285 men were eligible for the study. A questionnaire was mailed to the men who did not want to participate in a support group. After an intake, the same questionnaire was mailed to the men who were going to participate in a support group. From the group participants and non-participants, 260 questionnaires were returned. From these, 22 were excluded due to too many missing values or not meeting the inclusion criteria, leaving 238 men in our final database. Based on the intention to participate, 136 men were not interested in participating in a support group, 102 men expressed the intention to participate and from these, 48 actually did participate in an offered support group, but from one the data were incomplete so this person was not entered into the database.

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Background characteristics

The background characteristics from each of these groups are presented in Table 1.

Table 1. Background characteristics of the prostate cancer patients (N = 238)

	A Not interested, no participation in groups (n = 136)	B Interested, no participation in groups (n = 55)	C Interested and participating groups (n = 47)	Significant differences
Age				A vs B *
Mean (SD)	69.8 (8.2)	64.3 (7.2)	66.2 (7.8)	A vs C *
Range	42-86	48-77	51-81	
Marital status				
Single	21% (n = 28)	14% (n = 8)	15% (n = 7)	
Married	79% (n = 108)	86% (n = 47)	85% (n = 40)	
Socio-economic status				A vs B *
Mean (SD)	7.7 (2.3)	8.6 (2.1)	8.8 (2.1)	A vs C *
Time since diagnosis				
< 1 year	15% (n = 21)	15% (n = 8)	9% (n = 4)	
1-2 year	15% (n = 20)	16% (n = 9)	30% (n = 14)	
2-5 year	40% (n = 54)	40% (n = 22)	36% (n = 17)	
>5 year	27% (n = 36)	24% (n = 13)	26% (n = 12)	
Unknown	4% (n = 5)	6% (n = 3)	0% (n = 0)	
Stage of disease				
Local	68% (n = 92)	75% (n = 41)	72% (n = 34)	
Metastasis	32% (n = 44)	25% (n = 14)	28% (n = 13)	
Treatment				
Radical prostatectomy (RP)	21% (n = 29)	36% (n = 20)	28% (n = 13)	
Radiation therapy (RT)	17% (n = 23)	15% (n = 8)	15% (n = 7)	
Hormone therapy (HT)	46% (n = 63)	49% (n = 27)	53% (n = 25)	
RP & RT	8% (n = 11)	6% (n = 3)	2% (n = 1)	
Watchful waiting	7% (n = 10)	0% (n = 0)	2% (n = 1)	
Membership patients association				
Yes	52% (n = 71)	82% (n = 45)	72% (n = 34)	A vs B ‡
No	48% (n = 65)	18% (n = 10)	28% (n = 13)	A vs C ‡

* T-test, $p < 0.01$

‡ χ^2 , $p < 0.01$

Significant differences were found in age ($t(189) = 4.4, p < .01$) and socio-economic status ($t(189) = -2.3, p < 0.05$) between men who are not interested in support and men who are interested but do not participate. Between men who are not interested and men who are participating, differences were found in age ($t(181) = 2.7, p < 0.01$) and socio-economic status ($t(181) = -2.7, p < 0.01$). No differences were found between the groups for marital status, time since diagnosis, stage of the disease, and type of treatment.

Predictors of the intention and actual participation in support groups

In a logistic regression analysis it is explored which factors are most predictive for the interest in support groups. Background variables that were not different between the men who intend and who did not intend to participate in the offered social support groups, are not included in the analysis. Included in the logistic regression model were socio-economic status, age, the total score of the POMS, the total score of the IES, the total score of the SSL, contentment with the treatment in the hospital, number of prostate cancer specific problems, attitude towards group participation, social norms concerning group participation, perceived control, and the general health related quality of life. Table 2 displays the results of the analysis for the intention to participate in the social support groups.

Table 2. Odds ratios for interest in support groups (N = 238)

Factor	Odds ratio	95% CI	p
Lack of social support	1.03	1.00 – 1.06	0.03
Age	0.93	0.89 – 0.98	0.00
Attitude	1.67	1.40 – 2.00	0.00
Perceived control	1.73	1.07 – 2.80	0.03

Attitude towards support group participation and perceived control are the strongest predictors of interest in group participation. A more positive attitude and more perceived control for participation are predictive for more interest in participation. Also a greater lack of general social support and a lower age are associated with interest in participation. The final model predicts 79.1% correct which is an improvement of 20.4% over chance. Since attitude of the patients toward support group participation, as expected, is predictive for the interest in participation in a support group, it is examined which of the six components of the attitude scale are most important. This was also done by means of a logistic regression analysis with interest as dependent variable. Attitudes toward new ways to deal with the disease (odds ratio 1.2, $p < 0.05$, 95% CI 1.0 – 1.3), receiving information (odds ratio 1.2, $p < 0.05$, 95% CI 1.0 – 1.3) and coping with emotions (odds ratio 1.2, $p < 0.01$, 95% CI 1.0 – 1.3) are the components that are predictive for interest in participation. The same procedure was conducted for the perceived social support, since the total score is a significant predictor of interest, it is useful to know which components of social support are contribute to interest in participation. Only the subscale lack of daily support was predictive for interest in participation in a support group (odds ratio 1.2, $p < 0.01$, 95% CI 1.1 – 1.4).

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The second step is to analyze within the group that has interest in group participation, the determinants of the actual participation. For this analysis socio-economic status, age, the total score of the POMS, the total score of the IES, the total score of the SSL, contentment with the treatment in the hospital, number of prostate cancer specific problems, willingness to talk about these problems, perceived control, and the general health related quality of life. were included as independent variables. Table 3 shows the results of this logistic regression analysis.

Table 3. Odds ratios for actual participation in social support groups (N = 102)

Factors	Odds ratio	95% CI	P-value
Perceived control	3.14	1.41 – 7.00	0.00
Number of psychosocial problems	1.34	1.04 – 1.73	0.02

A higher perceived control and more prostate specific problems are the only significant predictors remaining after the analyzing process. Socio-economic status remains in the model with an odds ratio of 1.2, but is not significant ($p = 0.09$). This model predicts 74.7% correct which is an improvement of 20.3% over chance.

Discussion and conclusion

In this study we applied background characteristics, medical factors, psychosocial factors and constructs from the theory of planned behavior in their ability to predict interest in participation in a social support group and actual participation in these groups. There are some studies that compare support group participants and non participants of support groups (Berglund et al. 1997; Bauman et al. 1992). However, this is the first study to examine different factors in their interrelation, resulting in knowledge about the relative importance of different factors in the interest for and the use of prostate cancer social support groups. This is a key strength of this study, despite the relatively small number of group participants and the cross-sectional retrospective design.

The psychosocial factor that are related to interest in or actual participation, and that might trigger the formation of attitudes about participation, is a lack of social support in daily life situations. This is in line with the finding by Bauman et al. (1992), that support groups are appealing to those with lack of emotional support and /or weak social networks. In concordance with other studies, lower age and higher socio-economic status are related to interest in and actual participation in support groups. Katz et al. and Bauman et al. found the same result in their study on characteristics of participants of support groups (Katz et al. 2002; Bauman et al. 1992).

From the factors of the theory of planned behavior, a positive attitude towards group participation and a greater perceived control have a greater influence on the odds of having interest in support group participation than age or lack of social support. The components of attitude that are most important are learning new ways to deal with the disease, getting information about prostate cancer and discussing emotional aspects. The subjective norms do not have any predictive value in this study. Perceived control is the most powerful predictor of the actual use of social support groups. An increase of one unit predicts a four times higher chance of actual participation, given the interest in participation is present.

Conclusion

Factors that contribute to a higher interest in participation are a lower age, a higher socio-economic status, lack of social support, a more positive attitude towards group participation and a higher perceived control. Factors predicting actual participation are the number of prostate specific problems and perceived control. Perceived control also involves the physical distance that a patient is willing and able to travel. Physical distance is a major barrier to support group participation according to Bauman et al. (1992).

These results give useful information about the reasons why so few men participate in support groups. In the year 2000 approximately 33.000 men with prostate cancer were living in the Netherlands (Coebergh et al. 2004), where as the prostate cancer patients association, one of the organizers of support group activities, has only 500 members (1.5% of all patients).

In an evaluation study of support groups for cancer patients organized by the Helen Dowling Institute for psycho-oncology, it showed that not one prostate cancer patient was included (Remie et al. 2000). Further, a check in the administration of the same institute revealed that only 4% of 1331 registered patients (since 1996) are men with genitourinary cancer. Many prostate cancer patients experience psychosocial problems and a serious decline of

the quality of life in the first year after the diagnosis (Van Andel 2003), however, few men does in fact have interest in support groups or do participate. One factor is the lack of awareness of the possibilities to join a social support group. Eakin and Strycker (Eakin & Strycker 2001) found in their study that one of the main barriers to the use of cancer support is the lack of awareness of these groups which was found in 25% of men with prostate cancer. But even if men are aware of the possibility, attitude and perceived control are still the most important factors determining the interest and actual participation.

Practical implications

These results lead to some practical implications. Urologists or urology nurses could ask prostate cancer patients about their attitude towards group participation, explain the benefits and give information about the patients association or support groups. The medical care givers should also be alert on the social support system of the patient. If this system appears to be inadequate, referral to supportive care, for instance in the form of a support group might be considered. Concerning the content of and advertising for support groups, the educational aspects of groups should be emphasized since that is initially the main area of interest for a man with prostate cancer. Providers of support groups for prostate cancer patients should also be aware of the impact of geographical distance on the possibilities of group participation for this group of older patients.

By providing more understanding of factors that contribute or form a barrier to participation in prostate cancer support groups, this study has contributed to more possibilities for a better care for men with prostate cancer.

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